The Family Book

A resource for parents who have learned their child has a mental handicap

G. ALLAN ROEHER INSTITUTE

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Finding out

You have just learned that your child has a mental handicap. This may have happened for a number of reasons. It may have happened at birth or later on. Either way, the shock and surprise is similar.

It's important to know that a child with a mental handicap can be born into any family at any time. In fact, one in every one hundred children is born with some degree of handicap. If we include children with learning disabilities then that figure is about one in four. The risks are there for all births – we just don't let ourselves think about it too much and usually assume that "it will never happen to us."

Mental handicap is not a disease or a condition that can be cured. A child with a mental handicap will develop at a different pace mentally, physically and socially than a non-handicapped child. A child with a more severe handicap will need additional supports over a longer period of time to grow to his or her potential.

Feelings

If you have just found out about your child's handicap, you are probably in a state of shock. Like most people, you probably dreamed of having a perfect baby and chances are that your doctor or pre-natal instructor didn't discuss the possibility of having a handicapped baby. Also, most of us have little contact with handicapped people and don't have much information about mental handicaps.

If you're like most parents, you've probably lived with the myth of having and raising the perfect child. Well, welcome to parenthood! There is no such thing as the perfect child. One difference between having a handicapped child and having a non-handicapped child is that you will probably have to deal with this misunderstanding much earlier than other parents.

At some point, we all have to sort out why we have children and how many of our hopes and dreams we try to live through them. Eventually, we learn to temper our expectations and learn more about our children – *their* needs, *their* hopes and dreams.

However you eventually come to grips with the situation, right now you are probably overwhelmed by a flood of feelings and questions.

- What's in store for us?
- How should I treat this baby?
- What did I do wrong?
- How could this have happened to me?
- It's not fair!
- Can I love this baby?

There are no simple answers to any of these questions or feelings. Neither relatives nor doctors can tell you exactly what happened or predict your baby's future.

Feeling guilty

Living in an environment where there are constant warnings about eating,

drinking and exercising, it's quite natural to feel responsible for your baby's health. While nutrition and other precautions are important during pregnancy, in most situations there is no known cause for a child's handicap. It can happen to anyone, no matter what precautions are taken. You will not be doing anyone any favours by feeling guilty because guilt can paralyze. It's important at this time to turn your attention to things that you do have control over, like your family and your baby.

Dealing with the situation

First, start with the basics. Most newborns, whether handicapped or not, eat, sleep, burp, make noise, then sleep some more. Feed, love and play with your baby. His or her needs are no different from any other baby's. Later on there may be additional or different needs but the important thing for you and your baby right now is to get to know him or her as a delightful new person.

> . . . it doesn't take long because when you bring a child home from the hospital, it's not long before you suddenly see her as a real person. A personality of her own and a real child . . . no different than any other child. But there is a corner to turn because we all, after all, have our pre-conceived notions.[1]

In coping with the situation, it's important to take a look at yourself and your attitudes.

> We have to decide in our own lives how we feel about mental handicap. Are we sorry for people with a mental handicap? Are we afraid of them? Do we think mentally handicapped people are a class of people, a group, who are all different from somebody else? Do we think they're less good than we are because they don't happen to have such a high intellect, they don't happen to have such high ideas of what they should achieve, and that we can achieve a lot better than they can? Do we feel badly about them or do we feel better than they do?[2]

The time will pass . . .

This is probably one of the most intense periods of your life. From one moment to the next you can be feeling angry, sad, calm or frustrated. To complicate matters, those around you don't necessarily feel the same way at the same time.

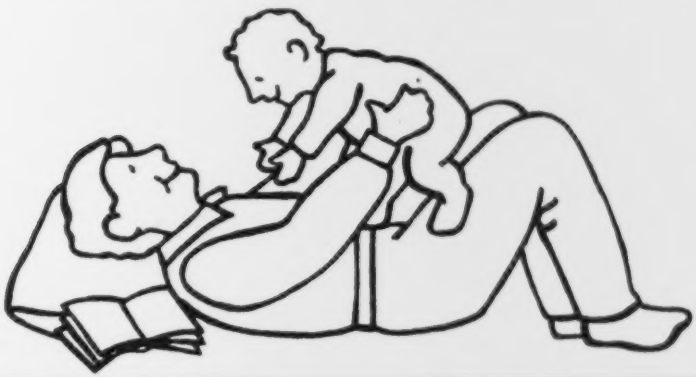
The most important thing to remember is that these ups and downs are normal and are your way of coming to terms with this new situation. The different feelings you may have, positive *and* negative, are natural. Talk about these feelings.

People react in many different ways. What's important is to realize that a natural process is under way. Our emotional reactions move on to more practical considerations.

Your questions may shift from "why did this happen?" to "how are we going to live with it?" You will probably focus more on day-to-day living and all its requirements.

In her book, *Does She Know She's There?*, Nicola Schaefer describes life with her daughter Catherine and, in this particular excerpt, her husband's relationship with his daughter.

> It had become his habit to collapse on our bed after supper for a quiet read with Cath lying beside him. She loved this, particularly when he put down his book and picked her up for a game. In fact, we realized after a while that she had formed a timing mechanism for this period of the day. She would lie cooing contentedly for about fifteen minutes, happy just to be beside him and receiving the odd absent-minded tickle. Then she would start to whine a bit and pull at his shirt, letting him know it was time for his undivided attention. After a few minutes of being heaved into the air, balanced on his knees, or sat on his stomach, she would agree to a compromise; he would lie her across his stomach and she would struggle to work her way over and down onto the bed while he continued reading. Then the cycle would start again.[1]



Coping with the situation will gradually get easier until one day you may experience the same feelings as this mother did.

> It took about a year until I came home from working in a clinic and said to my husband, "Today I had a problem that was greater than Jennie." My very wise husband said, "That must mean you're getting better." It did mean that I was getting better, but it took a few more very painful months, and easily another two years, until I believed again that I was more than the mother of a [handicapped] child. I decided that I did not want the major distinction of my life to be that I was the mother of a [handicapped] child. I finally was able to pick up the pieces of my life and proceed.[4]

Feelings change

Although you may have coped very well with the birth of your child, you may find yourself in a different kind of situation when neighbourhood children may not accept your child in the local playground. This may mean a whole new set of feelings or emotions you will have to deal with. As time goes on, however, things get easier because you develop skills to handle these situations.

It's better to know the truth – as early as possible – gently and with hope

Many parents go through months or even years of watching their child grow and develop, realizing that something is not quite right. They may take the child to doctors and other specialists who might say, "Let's wait and see. It's too early to tell." If you have had such an experience, the "wait-and-see" attitude can be disturbing especially if you still feel that something is wrong. When the day finally comes that someone tells you that your child has a handicap, you may be upset but you may also feel relief in knowing the truth. You were not imagining things all along and now you can begin to help your child constructively.

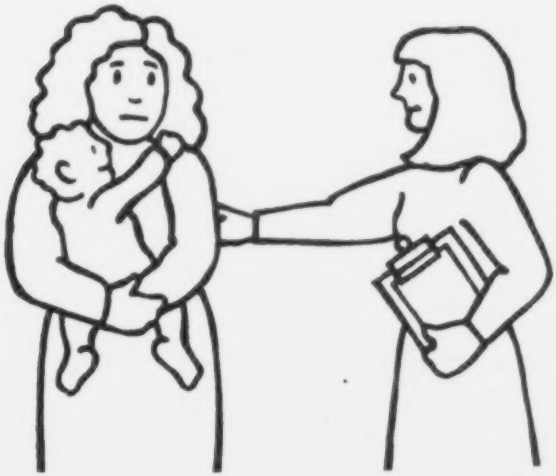
Looking ahead

After a time, most parents work out their feelings and settle down to a regular pattern of living. But there may still be the reactions of those people outside your circle of family and friends to deal with. Some will accept the child and often offer to help you out. Others may reject your child because of their

fear of mental handicap; a fear that is often based on ignorance and lack of understanding. It's important to anticipate these situations and prepare for them.

In summary, it may be useful to remember:

- Everyone reacts differently at a time of crisis. Don't let anyone tell you not to be emotionally involved with your child.
- There are many people who can help you in the community. Take the first step and ask them for support.
- Be prepared for rejection but don't be intimidated by it.
- Don't deny your feelings. Experience them as they happen.
- Seek out resources such as books or other people to help you in new situations which may seem threatening at first.
- Take every day as it comes.
- Look to a range of experiences in your life since your whole existence cannot revolve around one child.



The diagnosis

The "diagnosis" or "what is wrong with the child" does not usually give you much information. In some instances it indicates a biological reason for the handicap and may suggest things that can be done. For example, there are children who have metabolic conditions requiring medication or a special diet.

In most cases, however, the diagnosis will not tell you when your child will walk, talk or do other things independently.

At the time of diagnosis, and for a while after, a number of professionals enter your child's life and therefore yours. No matter who these professionals are, be they doctors or nurses, teachers or social workers, you have the right to express your point of view.

You may find yourself in contact with new doctors called in for consultation. There may be a great deal of information given in a short time from different people. It is important to remember that you provide the continuity in your child's life and that amid the tests, consultations and jargon, your child may become lost as a person. You also have the right to informed choices. Take your time and explore. It's your choice and you will have to live with it.

Professionals may attempt to predict a child's development on the basis of diagnosis. This is a limited approach for a number of reasons:

- It regards mental handicap as a medical condition which cannot be treated.
- It may lead parents to expect less of their child.
- It may label a child for life and thus prejudice anyone coming in contact with him or her.

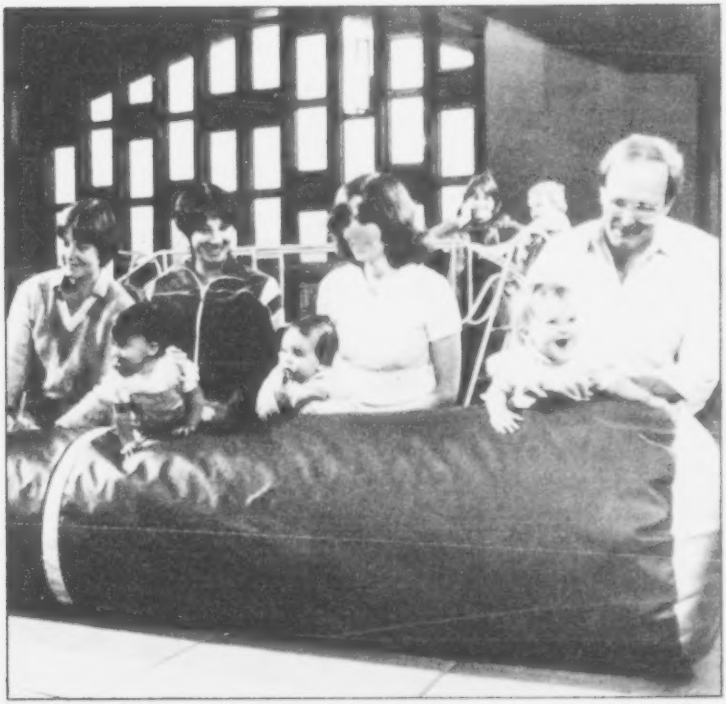
Time and time again children who were diagnosed as having a certain potential, surprised everyone by achieving well beyond anyone's expectations. But don't expect miracles. Rather, keep an open mind about the future and its possibilities. Although some doctors may act as though they have all the answers, this is not always the case. Give them feedback on how they affected you so that the next family that comes along will benefit.

Most doctors do not have sufficient medical or child development information to answer all your questions. They may have extracted information from a standard medical textbook to give you a general idea.

It's important to remember that mental handicap is not a "medical" condition. You will have to search out other parents, child development specialists and psychologists who live and work with handicapped persons in order to understand the situation.

More and more specialization in the medical and social professions often means that there is less known about the whole person in a community. It helps to find someone to sit down with you and interpret the reports and evaluations and to piece together the real information that determines a whole person.

Reaching out



After the birth of a child we all turn inward. We need time to get to know the baby, to show him or her off to family and friends, to begin to change our daily habits, and get some sleep! We need to be alone and with those close to us to come to terms with the impact of a new baby in our lives.

This is a healthy and important time. Sometimes, however, when we learn that our child is handicapped we have a tendency to keep to ourselves longer than usual. We may not feel like talking to anyone or are tired of explaining the situation or are unsure of people's reactions to the child. Or, we may feel that we have the situation under control.

There are many ways to learn to live with your child. You may want to come to terms with the situation in your own way. Or you may want to find out how other people do it and ask for their help. Although the close support of family and friends is very imporant, they are also emotionally involved. After a while you need a more neutral perspective, new ideas and energy. One thing is for certain, isolation means your resources will dry up quickly. Perhaps you can cope for now but what happens when things pile up?

People may isolate you. Due to their prejudice or shyness, you may be left out of natural support groups, for example, the groups of new mothers in the neighbourhood. It's up to you to take the first step. Although it takes a lot of courage and energy, you have to reach out to let others know what you need because they have no way of knowing.

Reach out to others for help in whatever way you feel comfortable. There are different types of involvement and you will want to work at your own level. You will have to set your own priorities.

You can start by asking yourself some questions:

- How many people can you count on when problems arise?
- Any family?
- Friendships you've allowed to lapse?
- People who will remind you that you're not taking care of yourself?
- A network of people you can depend on for different things in different ways and at different times?

But it's important to know that it's not all taking. The longest lasting relationships are those where people take *and* give.

We all have a tendency to reach out to the same people over and over again. Don't burn out your helpers. Sometimes you may feel that no one else or just a few people can care for your child as well as you can. Other people certainly won't if you don't give them a chance. If you don't share the responsibility for your child's care it will fall increasingly on your shoulders and those of a few others. It took one mother six months to take the plunge and visit her local library where a toddlers' group was being held. It took a lot of courage to do so, but now her young son has new friends to play with.

Be prepared for a variety of reactions – that's human nature. One father of a six-year-old with a number of challenging needs had the right idea: "Of course people look at him when we take him out. You will look at anything

you have never seen before. I had never seen a child like this until we had him and I would probably have stared at a handicapped boy too. It's not out of badness but natural interest."

Setting up a buddy system with a nearby family can help you to deal with unexpected situations, knowing that you have some support to fall back on. Also, using other families will give you ideas of your own, including relationships between brothers and sisters, and the involvement of other relatives.

If you have a young child, it may be a good idea to meet parents with older children so you get an idea of what to expect.

Reaching out to other people not only involves neighbours and old friends but also those who have lived with people with handicaps. Living with someone who has a chronic illness, for example, or a spouse who has just had a stroke, causes changes in a family and a need to reach out to others for help and support.

Exchanging babysitting is a good way to get to know other families in your neighbourhood. Lasting friendships have begun in just this way.

No matter how you reach out for support, it's important to remember that we all develop our own style. Do whatever feels most comfortable for you at your own pace.

Meeting parents who have children with handicaps

No matter how good your own neighbourhood or family support group, there may come a time when you'd like to talk to other parents of children with handicaps. Again, you should set your own pace in these situations.

If you're a new parent, you may already have come in contact with a Pilot Parents group at the hospital when your child was born. These are parents of children with handicaps who have come together for mutual support and who make themselves and their experience available to new parents. They often provide information kits at hospitals and will come to talk with you in your home if you wish. Pilot Parents groups can be reached through associations working on behalf of people with mental handicaps.

If you want to be more formally involved, Pilot Parents Groups are always recruiting new parents who are eager to pass on their experience and willingness to listen.

Here is an excerpt from a flyer describing the Pilot Parents' approach.

Why Pilot Parents?

Because when it is determined that a child is handicapped in some way, the parents need help, and

Because parents who have a handicapped child, who know the ropes and have accepted their son or daughter as a member of their family, can help.

Pilot Parents help with understanding and emotional support; give practical information about what the handicapping condition is; and suggest ways to care for children; give direction to resources and services in the community that can help new families.

Self-help groups of parents of children with mental handicaps have existed since the 1950s. Originally offering services such as education and vocational training, many associations are now helping to integrate handicapped people into regular services like public schools, housing and employment.

Here is how one local association has been helpful to families of children with mental handicaps.

The Gateway Association for the Mentally Handicapped was formed in Alberta in 1975 in order to support parents with handicapped children. One of the association's committees was the Family Support Committee. Members of the committee were speaking from personal experience when they expressed their feeling that counselling and advice from the medical profession left much to be desired since new parents were still being left to struggle on their own with their emotions after finding out their child had a handicap.

After a brain-storming session the committee decided on the following objectives:

- to seek out and support with understanding families of handicapped children;
- to help families in contacting available community services;
- to keep doctors, public health nurses, social workers and other professionals aware of what services are available in the community;
- to help create an accepting climate for handicapped persons in the community;
- to offer lists of publications helpful to parents.

To meet these objectives, the group advised hospital directors, pediatricians, obstetricians and hospital social workers, by letter, of their desire to offer moral support and understanding to new parents. Included with the letter was a brochure for new parents entitled "Let us help you" along with the group's calling card.

The group also held Family Study Practicums for parents and student practitioners in developmental handicaps. So, an opportunity was provided for the two groups to meet and get to know each other.

Most people, when faced with an unexpected event in their lives, feel they need to talk to people in similar situations. People who have lived the experience can provide much information which is not readily found elsewhere:

- information about experiences they have had with a child with a handicap;
- information about services, new trends, parents' rights;
- moral support in times of need;

- support in looking at the future, events that happen and how other parents have coped with them.

Whether you rely on your personal resources or become formally involved in organized groups, you should keep in mind that most people require support at some point in their lives. Although it is difficult to ask for help and you may be able to make a go of it for a while, when things pile up you will probably need outside help. Reaching out in whatever way you can, when you can, will gradually provide those resources.

The family

At birth, it's the baby that first receives most of the attention, the mother second, and the father a distant third! Once things begin to settle down, the needs and reactions of the couple, grandparents and other children must be taken into consideration. A focus on the family rather than on one individual is necessary if all are to learn to live together on a daily basis.

In the words of one parent,

> a handicapped person places stresses on the whole family, so that the whole family needs support and help in understanding a handicapped child's condition, his needs, present and projected, the extra demands his presence will place on the family. The entire family needs help with feelings. They need to know that it is alright to feel resentful, embarrassed, uncomfortable, and inadequate. They also need to be told about the joy, the love, the challenge and the opportunities for growth and fulfillment that such a situation can offer. As new children join the family, they particularly need help. The fact that they were born into a family with a handicapped person will not automatically equip them with the facility to explain their brother or sister to peers or to accept their feelings without trauma.[3]

The child with a handicap is a full-fledged family member, with all the rights, the responsibilities, and drudgery that goes along with that!

As normal a life as possible

On as before - Life certainly continues after the birth of a handicapped child. It may be somewhat changed and the way others react to you may have changed. To expect to settle back into old familiar patterns will just make things worse.

Take stock - How are you feeling? What are your resources? Don't invest too much in what others will think of you, or the fact that a neighbour or friend will marvel, "I don't know how you do it!" It takes too much work to appear well adjusted to others. You may have to give up some of your pride, but at least you'll retain a bit of your sanity.

Ask yourself:

- How do you get through each day?
- Does the baby cry for hours, or at least does it seem that way to you?
- What are your "trigger points" – that is, the times you want to scream, pound your head, or get out of the house?

- What is your daily routine?
- At what time and what kind of help do you need at different times in the day?
- Would watching General Hospital help even though you swore you'd never watch a soap opera?
- What about having a babysitter for a couple of hours?
- Would it help if someone else had a go at teaching Mary toilet training?
- What has helped in the past?
- What would be helpful now?

You may have a bewildering number of "helpers" around you, but you're surprised that you're not feeling any better. In the words of one parent:

> If only the practical offers of help were a traditional response to handicapped children – offers to babysit or grocery shop, offers to take our children for a walk around the block, offers to take them swimming, offers to give any reprieve, however short, which could give the parents, especially the mother, a chance to relax or do other things. Sympathy and pats on the back are nice, but we can get our solace most effectively from our fellow parents who do indeed understand. It's practical help, time and manpower we need.

Don't forget that life is more than the daily grind. Many parents have said, "It's not that difficult but we feel like prisoners. We'd love a night out or an uninterrupted visit with some friends." Take time out. It's important to take time with the other children, with your partner and for yourself.

Family life is important. Its success often depends on our ability to juggle the handicapped child's need for "stimulation" (exercise, programs) with the need for a normal daily life. What the child loses in one-to-one contacts he or she gains in terms of a happier family life, and the knowledge of the give and take involved in living with a group of people.

You may feel that you have to give that extra little bit of attention to the child with a handicap to compensate for the way he or she will be treated by others, or because he or she won't be able to achieve as much as the other children. The only guarantee with this approach is that the child will grow to expect that same attention from others and wonder why the rules are different from those at home.

Home is a home, not a treatment centre

Advice abounds. It is amazing how many "experts" there are, each with their opinion about how to best stimulate a child.

Infant stimulation, early childhood education programs and daycare centres have all begun to emphasize the importance of early intervention and parent involvement. Many of their suggestions have helped parents teach children how to become more independent. Knowledge about different activities, songs, and games can be a life saver when you have used up your store of "Three Blind Mice," "Old MacDonald," and so on. Also, ideas about such activities as toilet training can help your child when you've exhausted your own resources.

Often, "experts" ask, "What does your child need?" rather than "What do you need?" or "What do you need to help your child?" As a result, some parents, in addition to their work and other children, agree to do extra activities with their handicapped child, at the expense of their own and other family members' needs.

You have to ask yourself, "What do I think are the most important things my son or daughter needs to learn?" You know your children best. Let that be your guideline, as well as following charts or checklists which prescribe the next items your child needs to learn.

Also, ask yourself, "What are the needs of each member of my family?" Robbing Peter to pay Paul may work in the short term, but a parent who feels she has to put everyone else's needs first, or a sister who feels she never gets a ride to school because her brother or sister's "exercise" takes so much time, will begin to feel short-changed.

Of particular interest to fathers

Whether or not there is a handicapped child in the family, many fathers often have to make an extra effort to become as fully active in the raising of children as mothers.

A handicapped child may make the situation more complicated because as the father, you may feel like even more of an outsider than another parent. You may feel clumsy or inferior to your mate since she always seems so sure about how to treat the child. You may even feel jealous of her since she appears to get all the support and sympathy. Anger may even play a part in your reaction because you are expected to keep a stiff upper lip when that is the last thing you may want to do.

In many ways, women are better prepared for child-rearing since they often have more contact with children. They are also expected to be "experts" at raising children.

Because women have usually been seen as more "emotional," it may be easier for them to express their feelings thus making it easier to reach out for and receive support.

Unfortunately, this kind of situation is often not very helpful for fathers because they have fewer opportunities to learn how to be parents. Information and support may not be as readily accessible to men as it is to women.

So as the father of a handicapped child, what can you do to help yourself deal with the situation? A first step may be to take stock of your attitudes toward your family.

- How do you feel about the whole situation?
- Do you feel or react differently than the rest of the family?
- How do you deal with this difference?
- Do you take an active part in housework or child care?
- What are your responsibilities at home and how are they divided up with your mate?
- Who spends more time in the home? Who is the least involved in the home?

A second step may involve any or all of the following actions.

- Talk to your mate, family and other fathers.
- Practise expressing your feelings.
- Ask for equal time in the home and with the children.
- Ask for help with things you may not know how to do.
- Don't pull back but strike out for a more fair bargain.
- Spend some good time with your mate and family – they need what you have to give.

Here is one father's description of his attitude toward his son.

> At no time have I regarded Robin as a burden. I always felt and still feel that I'm fortunate to have a handicapped person in my family. It is through him that I've learned tolerance for other people of lesser abilities and different abilities. I know that my teaching has been deeply affected by him. I no longer judge a student on the basis of what he

can do in mathematics. I try to look at him as a person. I think no less of an individual who can't do mathematics. I don't think less of a person because he lacks some physical ability, like highjumping seven feet. So, Robin's handicap has been a very constructive influence in my life.[7]

Another father talks about how he and his family are coping with the situation.

All of our striving sounds deceptively simple. Don't fool yourselves. It's not as easy as it sounds. It would be so convenient if Tannis and I could experience identical emotions at exactly the same time. But that's just not the way it works. When I'm on a high, Tannis may be on a low and vice versa. If we didn't understand this, life for us could be a lot worse. This is when communicating really pays off. You have to know where the other person is if you ever hope to understand what he or she is feeling. Each of you has the responsibility of keeping the other fully informed and up-to-date on what you are experiencing. If you are the sort of person who does not open up and communicate easily you've got lots of hard work ahead of you. The work will be hard but you'll be amazed with the results.[8]

Working families

For financial, personal and professional reasons a large percentage of women with pre-school children are in the work force. If you had made plans to return to work after the birth of your baby, there is no reason you should not continue with those plans. Nurseries, daycare centres and babysitters can care for your child. It may mean a few adjustments for the sitter such as added support and resources, but it can be done.

Many nursery schools and daycare centres throughout Canada have adapted their programs to include handicapped children. The following are comments by an administrator of an integrated daycare program in southern Ontario.

As a result of integration we have seen non-handicapped children relate, interact and accept differences amongst their peers. They are naturally curious, asking questions as they would when observing any incongruity in their environment. To ask a volunteer "why are you so old?" is as natural a question as "why can't he talk?" Non-handicapped children have educated their parents about handicaps as well. It is very difficult for a parent not to become involved when their youngster, on

arriving in the morning, asks Mom or Dad to come and see what John can do now. Some parents even stay a while before going on to work to see more of what is happening, and many are as caught up in the excitement as we are . . . .

After several years in the system, many parents of children with special needs are aware of what they want for their youngsters as they enter the school system. They know what to look for in the way of programming and integration, and many now see these as basic rights.[9]

Whether or not to use alternative child care arrangements is a very personal decision. Returning to work also involves major changes for the family – who will do the housework, the shopping? What will happen if the child is sick? The majority of Canadian families find ways to juggle these different responsibilities. The decision of whether to work outside the home must take into account the entire family's priorities and needs. Had you decided to use alternative child care arrangements prior to the birth of your child? Have you used child care arrangements for your other children? A child with a handicap, like all children, benefits from contact outside the home. The child's needs are only one factor among many you need to consider on deciding whether to return to work.

Couples

Statistics show that staying together is not a foregone conclusion for any couple. Having and living with a child with a handicap may mean many things:

- It may be the best thing that ever happened to you and draw you closer together.
- It may be the final straw in a relationship that has had its share of difficult situations. Or most probably, it is one situation among many others that come your way that you have to learn to live with.

You won't always move at the same rhythm. Being together isn't the slightest guarantee that you'll react and adapt in the same way. Different backgrounds, expectations and ideas on being a parent, ensure that you'll both come to terms in your own way. You probably had very different ideas about what it means to live with a person who has a handicap. The whole experience involves your basic beliefs and feelings about what's important in life. You cannot force your own pace or your own way of handling your feelings on the other.

As a couple, you may share your private reactions a bit more easily with each other or you may not. One person may want to take a bit more distance from the other, or share the feelings or reactions with other friends or family members. But you can support each other, even if you are moving at a different pace and feeling and coping differently.

Here are some situations you may have to deal with:

- You may have to renegotiate your roles and responsibilities, to ensure that the day-to-day demands are redistributed to the satisfaction of each partner. This agreement must be reviewed periodically.
- There may be restrictions on your social life, your spontaneity, and your privacy. These are restrictions we all have to live with as new parents, but the situation may be more marked by the appearance of a handicapped child.
- Plan ahead. You may have to come to terms with yourself and your baby, but what happens the first time someone says:

  "That child belongs with his own kind."

  "You must be so strong to live with a handicapped child."

  "No, we will not accept John into our daycare."
- Share the power and the decisions.

- What are we going to do together?
- Who does what? Try to prevent a vicious circle where one person does all the work, the other feels left out and both of you feel resentful.
- Talk things out instead of keeping them to yourself. Hidden feelings of guilt or of blame on the other person for the situation can be poisonous for the relationship.

Here are the comments of one mother about her relationship with her husband.

> ... there are pluses and minuses. I really don't believe any one factor in a marriage can be pinpointed as a strengthener or strainer. There are too many variables affecting a marriage for such a simplistic explanation. The temperament of the individuals; the physical, emotional, and financial strengths; the problem-solving and coping skills; the commitment people bring – just to mention a few factors – all have some bearing on the strain a handicapped child brings to a marriage. From my point of view, I feel Robin has added more strength than strain. At least my husband and I are still living together after 37 years of marriage! For one thing, at those points in a marriage when you are contemplating divorce – intellectually, emotionally, or actually – the presence of a child such as Robin in the family is a major deterrent. The focus quickly changes from your own needs, wishes, and desires to your responsibilities, commitment, and the needs of the child. Somehow this helps you work through the problem and you find another way.

Brothers and sisters

> In the midst of all the crying and confusion when we first found out about our daughter's handicap, our son said, "Mommy and Daddy why are you crying? Sarah's alright. See, she is alright." He was right. She had not changed. There was no physical crisis or outward manifestation of a disease. She had not changed from the day before, but we had.

Young brothers and sisters often bring a welcome perspective on the arrival of a baby with a handicap. To them a baby is just that, a new addition, a rival and a playmate.

The effects and reactions of brothers and sisters are as varied as the per-

sonalities of the children themselves. The most important influence is the feelings that the parents communicate. If children sense that this baby is very different, they will treat the baby differently. Children may react differently according to the order in which they were born. A child with a handicap who has younger brothers and sisters may do well until there is contact with other children at play and school who may point out differences that had not been apparent until then.

On the other hand, the youngest in the family often benefits from more attention and more relaxed parents.

The greatest way to success is to provide an atmosphere where children feel free to talk about their feelings, both positive and negative.

Information is another important ingredient. Information about the handicap, about others' reactions and what to do about them all help to clear up the confusion and anger that may result if they are left in the dark.

Perhaps brothers and sisters of a child with a handicap learn to be realists a bit earlier than most. They learn that upsetting things happen to families.

a period of adjustment takes place, then life goes on, a bit differently perhaps, but pretty similar.

If information and feelings are not brought out into the open, children often think it is their fault and that they are the cause of the problem.

Take time with the other children – "their time." Don't share it with anyone else. You may be taking pains to treat everyone alike, but doctor's visits, assessments and programs may demand more *time*. Quality, rather than the quantity of time spent may reassure the child that he or she too is important, and that life does not revolve around the child with the handicap.

All children have a right to their childhood. We sometimes give more responsibility or decisions to the other children, so that the child with a handicap, no matter what his or her birth position is, becomes the youngest. Also, brothers and sisters have the right to their own time and space, rather than being babysitters and dragging their brother or sister along to their activities.

Here are some hints on helping your other children deal with the situation.

- Tell them that you understand they will probably feel sorry for themselves at some point but that won't really change things.
- Encourage them to try and understand the situation by learning as much as possible about their brother's or sister's handicap.
- Explain that your moods as a parent may change because of new demands made on your time, energy and resources.
- Tell them that their brother's or sister's handicap is not "catching."
- Encourage them to talk to their friends about the situation and pass on any information they have picked up.
- Explain that other children will probably tease them but if they don't let it bother them (or show that it bothers them) the teasing will usually stop.
- Urge them to talk to other children who have handicapped brothers or sisters so that they can share their ideas and concerns.

Instant integrators

Living at home with brothers or sisters to play and fight with provides the best opportunity for a child with a handicap to learn new skills and become more independent. What would take you a few weeks of careful planning to involve your child in the neighbourhood playground is done in five minutes when an older brother helps him use the teeter-totter.

Growing up together means they know their brother or sister in a different way than parents and professionals. A child who never dresses alone when parents are around is much more likely to do so when her sister wants her to hurry up!

> Someone outside the family could easily look at my life pattern and infer the fact I grew up in a home with a handicapped person. Certainly there has been some influence, but it has been more indirect than direct. Living with Robin has made me more aware of and sensitive to persons with special needs – that we are all persons with special needs – each asking for attention and understanding. Conversely, Robin's presence has not meant that I am always at ease in the presence of handicapped persons but I can always look upon them in a positive light without feeling distressed or disturbed. [7]

Growing up with someone who has a handicap may mean that you take the situation for granted, until people outside the family wonder, "why is he so slow?", "what makes her act like that?"

Brothers and sisters see their families as others see them, and sometimes begin to wonder if something is wrong with them. Especially with teenagers – as the pressure grows to conform, to be and act the same as everyone else – the "different" person in the family requires some explanation.

It helps to link up teenagers with someone outside the family – other teenagers with brothers or sisters with a handicap, family friends, counsellors. It's difficult to admit to parents that you're embarrassed and want to avoid your brother or sister.

On the other hand, it's normal that teenagers become more independent of the family, participating less in family outings and celebrations.

In a book written mostly by parents of handicapped persons, the sister of a boy with severe handicaps talks about her relationship with her brother and the influence it has had on her life. She looks back at their early years together and her total unawareness of her brother's handicaps. Recalling when she first became aware of his "differentness," she notes that it was the stares of people that began making her feel embarrassed.

Her embarrassment led to avoiding her brother by refusing to go on any family outings. Following this period she entered what she called "a phase of false pretenses." She forced herself to appear in public with her brother but only when she looked her best. She thought that if people were going

to stare, they weren't going to find anything wrong with her. Another reason for her behaviour was, as she admits, that she wanted people to think how wonderful she was for pushing her "poor" brother around.

A serious illness put her brother in hospital and it was then she realized that she really loved him for himself and not for what others thought of him. She finally accepted him as her brother and in fact made a change in her career plans so that she could work with handicapped individuals.[1]

Another child?

Very often the specific causes of a child's handicap cannot be identified. Experts speak about "probabilities" and admit they are often making educated guesses.

Genetic counselling does not provide a crystal ball, either. In addition to your family history, previous pregnancies and your physical health, genetic counsellors will combine that with the most up-to-date information about handicaps to project the odds of having another child with a handicap.

One family's experience is revealing. Their first child was born with Down syndrome. A few years later, after a rocky beginning including numerous hospitalizations, the baby was doing quite well. The mother expressed the desire to have a second child. The father agreed on the condition that an amniocentesis* be performed. The mother agreed to that but refused to have an abortion if the baby was handicapped. The situation was at a standstill for a few months until the father approached the mother saying that he realized that his request implied that he did not value his first child and that simply wasn't true.

On the other hand, many families whose first-born child has a handicap decide not to have more children. Whether they wish to spend more time with their child, don't want a second child in the first place or do not wish to risk having two handicapped children is not clear.

What is clear is that the decision is yours to make and that it *must* be one you both can live with five or ten years down the road. You need as much information as possible (not opinions or old wives' tales) and perhaps someone to sit down with to sort things out.

** a procedure by which amniotic fluid is taken from the mother's womb and analyzed for a number of conditions that could affect the baby.*

Community living

Many people nowadays feel more isolated than people used to feel in the past. Because the average family tends to move every five years, it is very easy to feel cut off from other community members. This also means that people are relying less on traditional supports such as their extended families and more on their own resources and on community services.

This idea of being self-sufficient and making it on one's own, can place many pressures on a family.

We often forget that we are all part of a community – a group of people who are interdependent and responsible for one another. Offering support and exchanging services are all part of being a community member.

In many cases, however, you will have to make the first move. You may have to reach out for help and perhaps offer something in return.

Community resources

Participation in community life is essential. Services which are available to the general public should and can be made available to you and your child. Schools, recreational and cultural facilities, health services, and religious centres are all resources which you and your family should be able to use as needed.

You may find, however, that these services do not always welcome a handicapped child. This attitude may vary from outright refusal of a child with Down syndrome for a pre-school program, for example, to more subtle suggestions in glossy magazine ads that handicapped children belong in places with "their own kind."

Let's look at some historical trends which have promoted these types of attitudes.

- Traditionally, society has perceived persons with handicaps as different.
- Large institutions were built away from communities to segregate individuals with handicaps.

Now we know that all individuals are capable of continued growth and development. To do so, they need contact with their environment and a variety of interesting people, places and things.

Over the years, parents have tried to change negative attitudes by coming together as an influential group. They established services in the community for their children. Many of these services, however, were segregated. More recently, there has been growing recognition that handicapped persons have the right to live and participate in their own communities so parents have become more active in promoting the use of community services for their children.

What are these services and resources? The following is a description of people and services you can expect to find in your neighbourhood, town or city for providing assistance when you need it.

Services may be public or private. These services operate with government funding, private fund raising, donations or through campaigns such as the United Way.

Formal or informal: Formal services for needs such as babysitting may take the form of a daycare centre or homemaker service while an informal arrangement may include your neighbour or a babysitter.

Community services are designed to meet a variety of needs:

- educational
- medical
- legal
- residential
- recreational
- religious
- financial

When your child is young you may need the following kinds of services:

SERVICES	WHERE TO LOOK
Health services	family doctors, specialists, dentists, public health nurses, well-baby clinics, physiotherapists, dieticians, nutritionists.
Social supports	family, friends, Pilot Parents (see p. 13 for more details), church groups, social service agencies, self-help groups, associations for people with mental handicaps (see p. 49 for more details).
Education for your child	daycare centres, infant stimulation programs, other families.
Information for yourself	public libraries, parents associations, consumer groups, books (see p. 51), parent education programs, in-home parent programs.
Relief services	homemaker services, babysitters, cooperatives, exchanges with other families, drop-in day care centres.
Material or financial help	tax breaks, subsidies (these vary from province to province), social services, crisis centres, family allowances.
Equipment/ adaptations to your home	requests to local service clubs, assistive devices programs (in some provinces), toy libraries.

Transportation	own car, public transport, taxis, car pools, church groups, school transport, specialized public transport, drivers provided by volunteer agencies, social service agencies.

As your child grows older, the services required may include:

Recreation programs	YM/YWCA, Boy Scouts, Girl Guides, church group programs, community recreation programs.
Relief services	camps, after-school programs.
Education	public or private schools.
Temporary alternative families	foster care, friends, family.

When your child reaches maturity the service needs will include:

Employment	employment training services, on-the-job support, job placement services.
Adult education	local school boards, local colleges, community colleges.
Legal services, estate planning, guardianship	attorneys, Bar Association, legal advocacy and consumer groups.
Financial services	insurance agents, bankers.
Social supports	social clubs, specific interest groups.

Finding a good service

From this list of services, you may be wondering how do you actually find a good service?

- Whom do you call?
- How do you know if they're good?
- What's a reasonable price to pay?
- What do you do if you're not satisfied?

There are as many services and professionals as there are problems. As with many businesses, the quality ranges from good, to mediocre to terrible. Without an idea of what you want, you are at the mercy of what's available.

It is up to you to find the help you need. Many people take what they find on their first try, and are not aware of their right to quality. In this age of consumerism, we are more likely to know more about purchasing a home or a car than how to find and use a community service.

We purchase the services of doctors and lawyers – whether directly or indirectly – through our tax dollars, and have a right to satisfaction. We need to know *what* we want, and *how* to go about getting it. In other words . . . satisfaction guaranteed or your money back!

Where do I begin?

Find someone (or a service) who knows about the area you are interested in. Names suggested by friends or relatives may be helpful although what suits them may not be good for you.

Most cities have general and specialized information and referral services and telephone hotlines. Local social service agencies, family doctors and your MP or MLA often have a good idea of resources available in a neighbourhood.

Once you have a few numbers to call:

- Can you obtain a description of the service?
- How does the receptionist/secretary sound?
- Is there a waiting list? If so, will they refer you to other resources?
- How does the service determine whether you are eligible? (Where you live, the type of problem, how much it costs?)
- After the first contact(s) do you feel encouraged and ready to make an appointment?

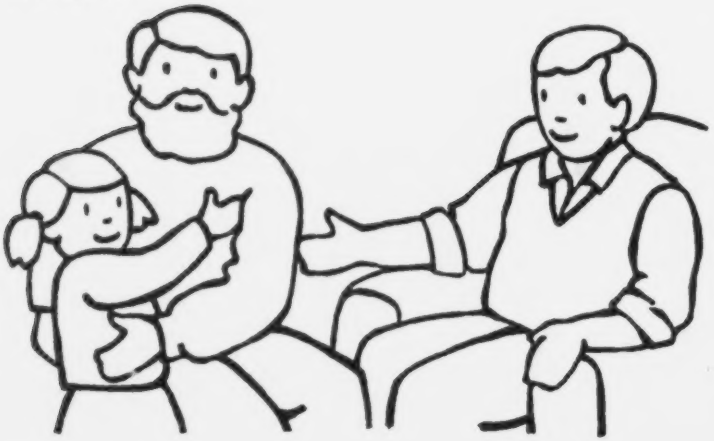
What do I want?

Preparation: Before you begin, write down the questions you want answered.

- Why are you using this service?
- What results do you expect?
- How will you know you've received good service?
- What has been most helpful in the past?

No matter what help or advice you receive, you are in control – you have to live with the results. Don't be snowballed by "experts." A true professional is someone who takes the time to listen, *understand* your situation and offer

appropriate support – not someone who tries to impress you with university degrees.



First visit or contact

- How does the office suit you? Is it close to home? Does the staff and the atmosphere relax you?
- If costs are involved, are they affordable? Is there a sliding scale?
- Do you feel involved in decisions? Are you given enough information? Do you understand it?
- Did you have enough time to tell your story?

A Plan

Before you and your child begin using a service, a plan should be layed out to let everyone involved know exactly what will happen, how, who will do it and when. This plan should be developed jointly by representatives from the service (or services you intend to use), yourself and your child (depending on the age).

An individual program plan or IPP should take the following into account:

- your child should be involved

  the child's likes and wants should be part of each goal that is set

  as much as possible, the child should participate in setting the goals

  goals should always be explained to the child

- the child's strengths should be used to set the goals
  - a list of the child's strengths should be made, what he or she can do, what he or she likes to do and other people who are willing to help
  - a list of the child's needs and possible goal areas should be made
  - the strength list should be reviewed to see how strengths can be used to help with needs
- small steps should be used to reach the goal
  - each step is to be something that can be achieved in a few days to a week
  - each step should be mastered before going on to the next
- it must be stated clearly who will do what and when
  - what the child will do or how he or she will be acting when the goal is achieved should be described
  - who will be responsible for helping the child achieve each step
  - when a target date is set for each step.

Here are some questions to ask yourself and those involved with your child:

- Are you all clear about what is to be done and who will do it? On a daily basis?
- Are long-term plans being made for you child's future?
- Do you feel that you and the others involved have enough information about your child, based on observations and evaluations, community services, in order to make decisions about the best programs for you and your child?
- Does the service your child is receiving focus solely on the child without taking into account the needs of the rest of the family?
- Does the service focus on one area of the child's development (e.g., walking, talking) without considering other areas?

What if I'm not satisfied?

Start by looking at yourself:

- Are you clear about what you want?
- Have you communicated that to the professional or service?
- Have you invested the energy, time or money necessary?

Then . . .

- Tell the person about your feelings.

- Ask for a plan/contract or a revision of the one you have developed.
- Look for a second (and third!) opinion.
- Would a consultant/specialist help?
- Look for a different type of service.
- Provide feedback to that person's supervisor or director (even if you do move on, that information may help change the situation for someone else).

Remember

If you are tempted to shop around, look closely at yourself and your service to see whether the problem can be worked out – before you move on.

Steps to integration

What does all this mean for you and your child? Well, it means that communities are generally much more accepting of people with handicaps than they have been in the past, but there is still a great deal of educating to be done. You may be required to act as a "pioneer" in your own community by being one of the first people to use a community service for your child. These are some ideas of how to go about it.

It is often wise to go slowly when introducing your child to a service which has only catered to non-handicapped persons. You may begin with a gradual introduction leading to fuller participation.

We all use different types of services at different points in our lives. But what happens to the child whose needs are not being met by the available resources? For example, your child may need physiotherapy that is not available in your community. Or you may have a child with Down syndrome or a child in a wheelchair who is refused admission to the local pre-school or daycare centre. What can you do about it? One way is to make the *means* available so your child can participate as fully as possible:

- Give as much information as possible about your child, the nature of the handicap and how you deal with it.
- Provide equipment or toys that would allow the service or program to meet the child's needs.
- Be there, as much as possible. You are in a better position to pick up changes in the situation, especially in the beginning, your very presence can be a support. Give phone numbers where you can be reached for your comments.

- Inform the service about resources that were helpful to you, e.g., neighbours are often more ready to lend a hand than we think.

For more substantial changes, such as making a physiotherapist available at the local medical centre, your presence and participation on committees or boards that make these decisions is an excellent way of encouraging services to adapt their program to suit your child's needs. Parents and parents' associations have been instrumental in lobbying for the creation or expansion of services.

The local parents' association can be a resource insofar as you ask it to be one. If you need help, don't hesitate to contact them. Many parents with children your child's age have experiences and strategies to share.

People, not just services, are resources. Information on support, relief and contacts with others are often provided by word of mouth. Look around for people who have lived in the community for a long time: housewives, business people active in community affairs, parish priests, and other voluntary associations. Get to know your community – find the points of entry – certain individuals are "social service centres" complete in themselves.

Use experts to explore the implications of community living on a day-to-day basis.

Integration means . . . to bring home the idea that normalization and integration are not things to be "done to people" – but expectations that the pattern of living experienced by families before the birth or diagnosis of their child should be continued as much as possible. You have a right to expect a normal life.

Access to services is a right, not a privilege. Don't beg – or be grateful for whatever services or professionals decide to do for you. A determined and informed parent can go a long way towards opening doors.

Working with professionals

From the time you learn your child has a handicap, you will probably have to deal with a professional in one way or another. As we mentioned at the beginning of this booklet, the professional who enters your child's life also enters yours. These individuals may include doctors, nurses, therapists, teachers or social workers. How can these people be useful to you and your child?

Here is a list of professionals you can expect to meet and what they can do for you and your child.

educators	(teachers, day care and nursery staff) provide information about child development and how to teach your child.
psychologists	evaluate and give suggestions about your child's social and emotional development.
social workers	provide counselling (individual, group, marriage, family); provide knowledge about community services and act on your behalf with other services.
family doctors	provide ongoing general health care for the family; refer to other specialists for further treatment when necessary.
pediatricians	provide general health care for children; developmental pediatricians have more in-depth knowledge about different handicaps.
geneticists	identify those conditions which are inherited and which could recur in other children in the family.
neonatologists	provide special health care to newborn babies.
child neurologists	diagnose and treat problems in the nervous system.
psychiatrists	look after the emotional development of the child (and the mental health of the parents!)
physiatrists	provide assistance for children with neuromuscular handicaps including exercises, braces and other therapies.
physiotherapists	provide information and exercises to help with the child's posture and ability to move around.
occupational therapists	provide assistance with self-help skills such as dressing and eating by using exercises, toys and assistive devices.

In the past, the parent/professional relationship has had some serious problems. Some parents have felt that they have been excluded from deci-

sions about their child's life. On the other hand, some professionals had unrealistic expectations of what they could do to help a child with a handicap.

More recently, parents and professionals have been working closer together and the results have been much more positive. Needless to say, there are still many professionals who resent parent involvement just as there are still parents who feel that professionals should have all the answers. What both sides sometimes forget is that although they are both working for the well-being of the child, each person brings a different set of experiences, training, attitudes and *feelings* to the situation.

An understanding of why the other thinks and acts in a certain way will go a long way in improving the parent-professional relationships. Here are a few tips:

Step back for a minute

Rather than saying that person doesn't know what he or she is talking about,

Consider

Perhaps he or she doesn't know very much about different handicaps or about day-to-day living with a handicapped child.

On the other hand

What do you really expect from this person? Do you know what you can expect from different professionals?

Or

When you've had your fill of doctors' appointments, evaluations, assessments, etc., you may feel that this person doesn't know how to help.

Consider

Maybe he or she is looking for the best service and for enough information to help you and your child. Parents are often accused of being "shoppers," that is, searching for different opinions and approaches for their child.

Or

When you feel this person is asking too much of you or your family,

Consider

Some professionals think that parents should be involved in all aspects of their child's learning or treatment.

On the other hand

Some parents feel that professionals should have all the answers and

should be able to provide service on demand.

In your dealings with professionals, however, you will find it helpful to remember that you have a number of rights which should be respected.

The right to participate

Nowadays, the team approach is popular among many professionals. They gather together to share information, discuss and decide on the best plan for the child and how they can each help. You have the right to participate on that team and help make decisions about programs or treatment for your child. Actually, you are the only constant and permanent member. Professionals may come and go, but over time you have the major responsibility for your child's well-being.

You are also a professional. As the result of daily contact with your child you become the expert on what the child can do, how he or she reacts in different situations, and the child's likes and dislikes. Therefore, you also have the right to be present at any assessments or tests that your child is undergoing.

Research shows that parent involvement in teaching can have a positive impact on their child's learning. As professionals place a growing emphasis on parent involvement in their child's program, they must also encourage and respect the parent's right to observe, have opinions and participate in all stages of a child's program.

The right to information

Participation is impossible without the appropriate information. Here are some questions to ask of people working with your child:

- What exactly is my child's handicap?
- What will this treatment or program mean for the child?
- What will it mean for our family, in our daily life?

Do the professionals and community services make sure that you are informed? If you are to have any control over the decisions which affect your family life, you must have access to information about your child, the child's handicap, and available community resources.

Parents have the right to be informed of their child's diagnosis from the beginning. This explanation should be in terms that you can understand.

The right to information includes:

- information about your child's and your own legal rights;
- any and all information about your child which a professional has on hand, including files and records;
- the right to the results of any evaluation done on your child;
- the right to seek a second opinion if you feel that your child has not been assessed or diagnosed properly;
- the right to a written, understandable explanation of your child's progress.

Decisions about programs for a child with a handicap are often made without considering the needs of the family. Also, some professionals may favour one treatment more than another. Families have the right to know all the options, the different resources, therapies and treatments available so that they can decide what is best for the child and the family.

The right to make decisions

Increasingly, organizations and governments are recognizing the right of parents to make decisions concerning their child. For example, one association states in its policy statement on the education of handicapped children that:

> There should be competent, voluntary and individual informed consent which is knowledgeable and autonomous and given by the individual, his parent or guardian without coercion or duress.[14]

Although this may seem self-evident, many parents fear that an insis-

tence on their rights may lead a professional to withdraw the service or change his or her attitude toward the child.

You are the legal guardian of your child and as such have the right to make informed decisions about the child's future. You have the right to participate in setting priorities in the child's program. Each family member has a number of different needs. You set priorities depending on which needs are most important. A professional may suggest that you practise climbing stairs with your child when you live in an apartment with an elevator, while you feel that toilet training is the most important program area. Ask yourself, "What do we need most to get along on a day-to-day basis?" And keep the answer in mind when you are asked to decide on the child's program.

The right to service

As a parent, you should not have to beg for services for your child that are a legal and human right. If you need short-term or long-term respite services you should not be made to feel guilty or overly demanding. You have a right to pursue any and all types of services that you feel would be beneficial to your child and family.

The right to advocate

You more than anyone else want the best for your child. Professionals and service agencies often do their best but still have to work with limited resources and many demands on their time. While the community as a whole seems able to help you out, when it comes down to practical things, you may still need to speak out on behalf of your child in order to get what is necessary. In addition, you may want to advocate on behalf of others in similar situations.

Messages such as, "You should make do with what you have," or "You're an idealist to ask for that kind of support," are sometimes used to discourage parents who want something better for their child. But if parents had not had the courage to advocate for their children years ago, there would have been no progress in services to handicapped people at all.

> It wasn't luck that opened programs so that young people could be like others. It was hard work and determination – the endless meetings, briefs, conferences, then back to school, daycare centre . . . It was knowing that . . . youngsters needed that extra concern and encouragement to share the joy of living and achieving in full measure. Our town needs more people who can do that.[5]

The right to advocate means the right to:

- be present at everything concerning your child;
- participate in every decision involving your child;
- lobby for changes in approaches or services that you feel are inappropriate.

Becoming a partner

What can you do as a parent to ensure that your child is receiving the best service available, and that the professionals involved are working in your child's best interest?

One of the most important things a parent can do is to become as informed as possible. Find out all you can about your child's handicap and the types of things that can be done to minimize it or prevent it from becoming worse. Find out how various systems work including health services, education and government services at different levels.

If all this sounds overwhelming, remember that you can begin on your own with your own doctor in your own community. Most of the information you will need will come as you move on to other professionals and services.

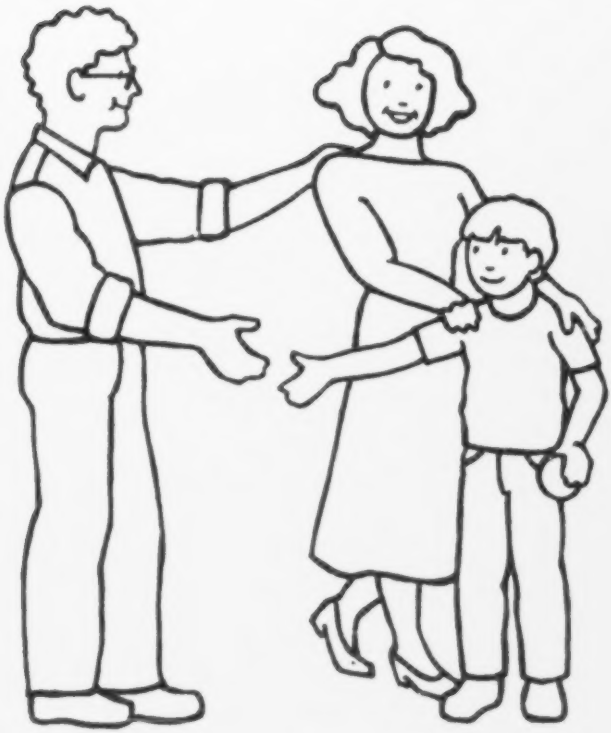
In making sure that your rights are respected, you will have to be assertive. This does not necessarily mean being aggressive. The parents of one handicapped child defined assertive behaviour as "the direct, honest and appropriate expression of feelings, opinions and beliefs, without violating the rights of others."[6] If you disregard the rights of those involved in your child's life, you may be hurting your chances of being taken seriously as a competent and informed team member.

A parent whose child was discouraged from continuing to attend a regular public school because of her handicap took some assertive action of her own. She called the education supervisor in her area and then asked to observe her daughter in the classroom to see if there were indeed problems. The child seemed to function as well as anyone else in the class. As a result of her calls and her presence, education authorities were embarrassed by the whole situation and told her there had been a misunderstanding and that her daughter could continue going to public school.

This parent notes,

> This was one of the few times that I used strong tactics to get Becky what she needed. Usually a more conciliatory approach is better. I recommend using aggressive methods only when there is no other

alternative. A parent must protect a child's best interests and sometimes this requires one to be unpleasant. I think that most of the time when someone is not doing what the parent feels is best for his child, it is because the professionals do not see the situation in all of its aspects. They take a narrow view that includes their own fears and prejudices. If at all possible, a parent should try to give professionals as much information as they need to see the child's whole situation.[7]



An equal partnership

Parents are not only becoming more involved in decisions made about their children but they are also becoming partners with the professionals who are helping their children.

If you want to become an equal partner, you should know your child's needs and try to find programs and services to meet those needs. You should give professionals all the information you have about your child because you know your child best. Keeping the communication lines open throughout your involvement with a program or service is a good idea since you may want to change some things about your child's program.

In order to keep up to date on everything that is happening, keep asking questions. For example, you may ask,

a psychologist: "Do you think Amanda needs another psychological test?" The test may only be part of a routine already established by the agency and have no bearing on Amanda.

a clinical team: "Why can't I sit in on the case conference on Lynn? After all, I'm the parent." Case conferences are often called after a series of tests and parents are often not invited but receive only a summary.

a doctor: "Could I have a letter outlining our discussion today about Tony?" This is not always done but is useful for future reference. The greater part of conversations is usually forgotten after a period of time.

a program director: "Could I have a report on Justin's activities?" It is helpful to refer back to see how a program is meeting your child's needs. If it is not, look around for something else.

It is important to keep in mind that as your child grows, you may find it more difficult to work with professionals because you may both be discouraged about the progress your child has made. It is much easier to be optimistic about an infant's potential than that of an adolescent. Again, it is essential to keep the communication lines open so that the relationship you have built up with a professional does not break down.

Your responsibilities

Professionals are trained to provide a service, and to bring various skills and resources to support or change situations. You have the *right* to receive a good service, but also the *responsibility* to hold up your side of the bargain:

- to share the appropriate information;
- to make decisions and carry out parts of the contract.

The success of your contact with a doctor, therapist or daycare centre depends on how well you work *together*.

The future

Raising children includes worrying about what they will do and what will happen to them when they grow up. Whether your child is handicapped or not, it doesn't get any easier as the child grows older. Physical demands will give way to emotional demands, and the focus of your experience may shift from the family to the community.

As your child grows, you may sometimes have the urge to withdraw and protect your child from the demands of the world, but it's important to share your concerns with others and help your son or daughter find his or her own way.

Some of your future concerns may include financial planning, trust accounts and guardianship. The most common worry of parents with handicapped children seems to be, "who will take responsibility for my son or daughter after I'm gone?"

Any decisions you eventually make about any of these concerns can and should involve your son or daughter to whatever degree that it is possible.

It's also important that you build up a group of friends who care about your son or daughter and like him or her as a person. In the following excerpt, Nicola Schaefer describes her 21-year old daughter Catherine and their network of friends:

> Normally when I leave home for a few days our friend Zana moves in to care for Cath. Zana appeared in our lives during a summer recreation program, in which she was working, and since then she has virtually become part of our family. As long as Ted or the boys are around to lift Cath, she can pretty well replace me. She's resourceful and bright and she makes me laugh. . . . Cath enjoys my absences because Zana often loads her into the van and takes her to parties with her friends. "Why not?" she says, "It's time she had a few nights out."
>
> It's good that Cath is getting used to being cared for by different people and in different places (last summer she stayed, very sucessfully with a neighbourhood family while the boys and I were in England) and it's also good for me to know that she survives perfectly well without me. The thought of her living somewhere else permanently used to make my stomach lurch and my ears hum with horror. Now, though, with the help of Zana and David and other friends, I'm beginning to look at it from Cath's point of view, rather than my own. And when I do that I realize she has as much right as the boys to leave home eventually.[8]

Just like anyone else, individuals with a handicap need the opportunity to become adults, to take risks, to grow, and to do adult things like solving problems. Having a mental handicap does not necessarily mean that one also has a social handicap.

Planning ahead for a son's or daughter's independence also means that you have to look to your personal interests as well. All parents have to deal with an "empty nest" and as the parent of a person with a handicap, you will be no exception. Because the demands on your time have probably been great, you may suddenly find yourself with relatively little to do. However,

you can look forward to developing other interests, seeing friends and spending more time with your mate.

In helping your son or daughter become independent, your attitude about what is possible can have a great impact on his or her future. Here again is Nicola Schaefer's description of how she sees her daughter (who has some very challenging needs) living after she moves away from home.

> Until recently the idea of her living in her own apartment was ludicrous. However, I've now met many people across Canada, some with even greater needs than Cath, who are living happily and successfully in small houses or apartments, usually with one or two friends who are handicapped, and with the necessary assistants either living in or being there on a shift basis. Judging by set-ups I've already seen, I think one of the most attractive and practical ideas for Cath would be an apartment. There are several blocks near us which are wheelchair accessible, have a swimming pool and nice surrounding neighbourhoods in which to go for walks, and are as close as we are now to such amenities as hospitals and stores; in fact the only basic necessity not already in place would be her bathtub, which could easily be transferred.[19]

A final word

We hope that reading this booklet has provided you with some encouragement and hope for your child's and your family's future.

A positive and optimistic approach has been emphasized to give you a glimpse of what is possible.

We realize, however, that reading this booklet is one thing and dealing with the day-to-day reality is quite another. No growth or process of change is smooth or without difficult periods. The most important thing to remember is that there are many people, groups, organizations, books, courses and other resources available to help. If this booklet encourages and assists you to find those resources, then its goal will have been reached.

Resources

These are addresses of associations for persons with mental handicaps throughout Canada.

Canadian Association for Community Living
Kinsmen Bldg., 4700 Keele Street
Downsview, Ontario M3J 1P3

British Columbians for Mentally Handicapped People
1027 West Broadway, Vancouver, B.C. V6H 3Z2

Alberta Association for Community Living
11728 Kingsway Avenue, Edmonton, Alberta T5G 0X5

Saskatchewan Association for the Mentally Retarded
3031 Louise Street, Saskatoon, Saskatchewan S7J 3L1

Association for Community Living - Manitoba
45 - 825 Sherbrook Street, Winnipeg, Manitoba R3A 1M5

Ontario Association for the Mentally Retarded
1376 Bayview Avenue, Toronto, Ontario M4G 3A3

Association du Québec pour les déficients mentaux
3440, avenue de l'Hôtel-de-Ville, Montréal (Québec) H2X 3B4

New Brunswick Association for Community Living
86 York Street, 2nd Floor, Fredericton, New Brunswick E3B 3N5

CAMR - Nova Scotia Division
83 Portland Street, Dartmouth, Nova Scotia B2Y 1H5

CAMR - Prince Edward Island Division
P.O. Box 280, Charlottetown, P.E.I. C1A 7K5

Newfoundland Association for Community Living
P.O. Box 5453, St. John's, Newfoundland A1C 5W4

Yukon Association for Special Needs People
Box 4853, Whitehorse, Yukon Y1A 4N6

Recommended reading

Baker, B.L., Brightman, A.J., Heifetz, L.J., & Murphy, D.M. (1976). *Behavior problems.* Champaign, Ill.: Research Press.

Barnard, P.E., Demery, M., Dickerson, M., Kambouris, A., & Lynch, E. (1977). *You and me.* Lansing, Mich.: Wayne County Intermediate School District.

Brown, S.L. & Moersch, M.S. (Eds.). (1978). *Parents on the team.* Ann Arbor: The University of Michigan Press.

Cairo, S. (1985). *Our brother has Down's syndrome.* Toronto: Annick Press.

Des Jardins, C. (1980). *How to organize an effective parent/advocacy group and move bureaucracies.* Chicago: Coordinating Council for Handicapped Children.

Featherstone, S. (1980). *A difference in the family: Life with a disabled child.* New York: Basic Books.

Forest, M. (1984). *Education/integration: A collection of readings on the integration of children with mental handicaps into regular school systems.* Downsview, Ont.: National Institute on Mental Retardation.

Hanson, M.J. (1977). *Teaching your Down's syndrome infant: A guide for parents.* Baltimore: University Park Press.

Honig, A.S. (1982). *Playtime learning games for young children.* Syracuse: Syracuse University Press.

Koch, J. (1976). *Total baby development.* New York: Pocket Books.

Markel, G.P., & Greenbaum, J. (1979). *Parents are to be seen and heard: Assertiveness in educational planning for handicapped children.* San Luis Obispo, Cal.: Impact Publishers.

National Institute on Mental Retardation (1986). *Making a difference: What communities can do to prevent mental handicap and promote lives of quality* (Vols. 1-5). Downsview, Ont.: Author.

Perske, R. (1981). *Hope for the families: New directions for parents of persons with retardation or other disabilities.* Nashville: Abingdon.

Perske, R. (1980). *New life in the neighborhood: How persons with retardation or other disabilities can help make a good community better.* Nashville: Abingdon.

Pivato, E. (Ed.). (1984). *Different hopes, different dreams.* Edmonton: Academic Printing and Publishing.

Schaefer, N. (1982). *Does she know she's there?* (updated ed.) Don Mills, Ontario: Fitzhenry & Whiteside, Ltd.

Turnbull, A.P., & Turnbull, H.R. (Eds.). (1978). *Parents speak out: Views from the other side of the two-way mirror.* Columbus: Charles E. Merrill.

Wolfensberger, W. (1972). *The principle of normalization in human services.* Downsview, Ont.: National Institute on Mental Retardation.

Notes

[1] David Vickers, as quoted in the film *Medical Aspects of Mental Retardation: Ethics and Morals*, NIMR, 1983.

[2] Dr. Sandy Lowden, as quoted in the film *Medical Aspects of Mental Retardation: Attitude and Management*, NIMR, 1983.

[3] Schaefer, N. (1982). *Does she know she's there?* (p. 61-62). Toronto: Fitzhenry & Whiteside.

[4] Ziskin, L.Z. (1978). The story of Jennie. In A.P. Turnbull & H.R. Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 75). Columbus: Charles E. Merrill.

[5] Helsel, E. (1978). The Helsels' story of Robin. In A.P. Turnbull & H.R. Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 113). Columbus: Charles E. Merrill.

[6] Morton, K. (1978). Identifying the enemy – a parent's complaint. In A.P. Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 147-148). Columbus: Charles E. Merrill.

[7] Helsel, E. (1978). The Helsels' story of Robin. Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 104). Columbus: Charles E. Merrill.

[8] Jarvis, T. & Jarvis, T. (1984). *You are not alone: A parent to parent handbook dealing with the realities of life with a child recently diagnosed as having a handicap.* (rev. ed.). (p. 8). London, Ontario: Author.

[9] Mosten, S. (1978). Evolution of an integrated service for preschool handicapped children. *Déficience mentale/Mental retardation*, 28(3), 22.

[10] Helsel, E. (1978). *The Helsels' story of Robin.* Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 100). Columbus: Charles E. Merrill.

[11] Philpott, J.L. (1979). By the waters of Babylon: The experience of having a Down syndrome child. *Pastoral Psychology*, 27(3), 159.

[12] Helsel, E. (1978). The Helsels' story of Robin. Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 100). Columbus: Charles E. Merrill.

[13] *Ibid.*

[14] National Association for Retarded Citizens. (1971). Policy statement.

[15] Anglin, B. & Braaten, J. (1978). *Twenty-five years of growing together: A history of the Ontario Association for the Mentally Retarded.* (p. 91). Downsview: Canadian Association for the Mentally Retarded.

[16] Jarvis, T. (op. cit). p. 13.

[17] Burke, J. (1978). Face to face in times of crisis and over the long haul. In A.P. Turnbull (Eds.), *Parents speak out: Views from the other side of the two-way mirror.* (p. 91). Columbus: Charles E. Merrill.

[18] Schaefer, N. (op. cit). pp. 249-250.

[19] *Ibid.* p. 251.

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